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ABSTRACT

Teachers and other school staff need special preparation in order to effectively help meet the needs of the terminally ill child. Problems faced by special education personnel in dealing with the dying child include the sparcity of information on the subject and the tendency to avoid the issue of death. (DB)

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Dying and Death of Children: Implications for Special Education

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Children die. It's not fair, it's not right, but they die anyway. And in their dying and death they impact on family, peers, school, and other associated groups in ways that we certainly feel, but don't understand, and are only now even beginning to examine.

The purpose of this paper is to share with the reader some of the impressions, the reactions, and the little data that have resulted from an inquiry into this issue of terminally ill children by two special education administrators.

We found no single voice, no simple explanation, no one philosophy relating to the dying of children. Attitudes are diverse, skills are limited, information is lacking, and community and school-based programs to meet the needs specific to these children and their families appear nonexistent.

A question common to this and other school issues is, "Why should it be the function of the school to provide services around this issue?" One of our tenets is that the need exists, the role of the church and family to meet the needs is diminished, the resultant impact on the school is great, and it therefore rests with the school to either continue to ignore or ineffectively deal with the issue when it arises, or to begin considering some program options.

From our search of the literature, work with the terminally ill, interactions with other professionals in related fields, and discussions with educators, social workers, funeral directors, psychologists, and physicians we have derived some points for further speculation:

1. To effectively help others in the care of the dying, one should first engage in some process of introspection to better understand his own attitudes and feelings toward death. Some 300 university courses on some aspect of death are now available. These courses tend to be over-subscribed and run the gamut from one four-year training program for funeral directors (University of Minnesota) to a plethora of one semester courses. These courses arise from a number of disciplines including sociology, religion, philosophy, psychology, medicine, and nursing. Examples of their primary focus might include any of the following areas: fear of death; study of grief; life after death; cultural study of death; consumerism behavior; suicide; euthanasia; and, financial preparation for death.

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2. Of these hundreds of courses, few attend to helping teachers and school staff through content, instructive procedures, and processes for attending to the needs of dying children. When the two nouns death and children are put together in titles of courses, lectures, or research, it is usually in the contexts of explaining death to children or dealing with children concerning the death of significant others. The multitude of issues involved in dealing directly with terminally ill children are by comparison to the former contexts, unexplored.

3. Special Education personnel are generally perceived as having a wider tolerance for and understanding of atypical children. We speculate that general educators may view the domain of Special Education as the most appropriate setting and personnel for also dealing with dying children. The authors feel this not to be the case, that this issue has school-wide impact, and that staff resources should not be so restrictive as to view the issue as belonging to Special Education.

4. Dying children have needs specific to their dying. Elizabeth Kubler-Ross indicates, "There is a conspiracy of silence, withdrawal, and dehumanization that surrounds the terminally ill (Kubler-Ross, 1969)". Dying children need intervention; they do not need to be avoided. The grief process, whatever that is for an individual child, needs to be identified, respected, and participated in by whomever the child wishes to include.

   Kubler-Ross and others have given us a body of literature on the dying process as it applies to adults. We are not so well endowed by a subset of critical thinking on the same process when it applies to children.

5. Involvement with terminally ill children will also bring school personnel into a parallel involvement with the families of their children. Several studies indicate that serious marital difficulties develop in up to 70% of families having terminally ill children, further compounding the problem of the family's ability to meet the child's needs.

   In the most intact of families the dying of a child is an incomprehensible debilitating experience, and as such it at least temporarily draws away the defenses and the coping abilities of the family members. It is into this arena that the school personnel who choose to deal with these children will place themselves.

The conscious decision to plan a thorough program for a terminally ill child is not an easy one. The technology is sparse. The perceived ripple "effects" may tend to make the strongest

administrator blanch on first thought. We further believe that if such programming is to take place it should have the benefit of foresight and pre-planning by only school or related agency personnel who themselves choose to be involved.

We feel that the dying child has the right to not only experience life, but should also be afforded the opportunity to deal with the imminence of his death.

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